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Knowledge and skill needs of home caregivers and their care burden perceptions

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Abstract

Research problem/aim: Family members are increasingly taking more responsibility for patient care. We were conducted this study to determine knowledge and skill needs of in-home caregivers and their care burden perceptions.

Methods: The study was designed as descriptive study. The universe of this study included 350 patients who were registered in a Public Hospital Home Care Services Department by year of 2016 and the research sample consisted of 161 patients and patient relatives. Data was collected to use Patient and Caregiver Forms, Care Burden Scale, and Barthel Index. We were calculated the data with percentage, average, standard deviation, independent samples t test, Mann Whitney U, Kruskal Wallis tests.

Finding: Total Care Burden Scale point is 41.32 ± 13.20 , caregiver's age, marital status, educational status, economic status, to get help about care and receiving care duration do not affect CBS points, female caregivers have less CBS points than male caregivers and this difference is statistically significant ($p < 0.05$), the least skill level part of caregivers are care and prevention of decubitus, patient handling with the proper method, pay attention to their own body mechanisms, wound care, vital measurements, genital care, stress management and constipation.

Conclusion: Caregivers have in a low level of training about care and need knowledge and skills according to patient needs. Care burden of men is higher than women.

Keywords: Caregiver burden, dependency, family caregivers, home care services, knowledge.

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1. Introduction

World Health Organization has defined the home care as “providing care service at home by formal and informal caregivers”. Formal care consists of health and social utilities and informal care consists of patient’s relatives as wife/husband, daughter/son, his/her family and non-kin group as patient’s neighbors, friends or volunteer caregivers (WHO, 2008). Even though home care services are gradually increasing, “home care” is quite difficult process for both caregiver and the person who receives care in our country and the world. Increasing number of women participating in working life, conversion to nuclear family, downsizing of houses and economic difficulties complicate the care of needy people in their own family (WHO, 2008). The care which is given by patient’s family is not limited to only one aid. It includes many responsibilities such as health care, medication administration, personal hygiene (bathing, eating, dressing, toilet etc.), social services planning, shopping, housekeepin, economic administration and help, sharing a house (Aşiret and Kapucu, 2012). Nowadays, family members are increasingly taking more responsibility. Hence, nurses, doctors and other healthcare professionals should monitor the caregiver’s communication, knowledge, behaviors and attitudes about disease and care; focus on caregiver’s abilities and help them to develop positive behavior. At the same time, protection of caregiver’s physical and psychological health and support for them to take less care burden during the care should be provided (Gopalan and Brannon, 2006; Salama and El-Soud, 2012).

In the literature, burden of care is defined as a complex structure. There are it's negative objective and subjective impacts and consequences (e.g. emotional, psychological, physical health impact, economic and social issues, deterioration of family relationships, and feeling of loss of control emerged by the care undertaken)(Küçükgüçlü et al. 2009). For this reason, the fact that health professionals give counseling to caregivers on help and guidance services for their needs may be beneficial for them and their patients by supporting the caregiver's efforts to seek help (Aşiret and Kapucu, 2012; Gopalan and Brannon, 2006; Mollaoglu et al. 2011; Salama and El-Soud, 2012). Home health care services are given to patients with serious problems such as bedridden, disabled, cancer or muscle diseases in our country. There is no integrated service with private hospital services. Patients are not provided with an integrated service with hospital services. Most of these patients are cared for by their families at home in Turkey. We were conducted this study to determine knowledge and skill needs of in-home caregivers and their care burden perceptions.

2. Materials and methods

2.1. Study design

This research was a descriptive study.

2.2. Setting and sample

The research population was made up of 350 patients who were registered in a Public Hospital Home Care Services Department by year of 2016 in ...city. We got the addresses 250 patients who receive home care at least twice in six months and more.

The study inclusion criteria for the caregivers: being at least 18 old age, primary caregiver, able to communicate in Turkish, have no visual and hearing impairment and caregivers who care at least twice in six months and more at home. A primary caregiver is the person (e. g. a family member, relative, or friend of the patient) who takes primary responsibility for someone who cannot care fully for himself or herself. He/she is spent the most time with the patient, providing the main needed day-today care, assistance, and support to patient. All of the caregivers who accept to participate without sampling were added into the sampling. Next, ten caregivers that were involved in the scope of the research were pre-applied. The data of the pre-administration group was not included in the survey. The patients and/or caregivers (50 participants) refused the study, 20 of them changed their address (the address information of the institution has not been updated), and 9 of them could not be reached at their address though they were visited three times. Hence, 161 people participated (67% of participation level) in this study.

2.3. Ethical considerations

A University Clinical Researches Ethics Committee approval (15-KAEK-194) and institutional permission were obtained for the research. Verbally consent be obtained from the participant and all participants were informed about the study.

2.4. Measurements

The data were collected by two different question forms prepared for patients and caregivers using literature, Caregiver Burden Scale, and Barthel Index. In order to evaluate the forms' intelligibility which will be used to conduct the study, ten random patients and their caregivers were selected and a verbal consent was taken from each of them. Pre-application was made and necessary regulations were made on question forms. Patients and caregivers who participated in pre-application did not participate in this scope of research.

2.4.1. Patient Information Form (PIF) is a question form questioning socio-demographic characteristics and home care services of patients who received home care. It was prepared by researchers by reviewing literature.

2.4.2. Caregiver Information Form (CIF) is a question form to questioning socio-demographic characteristics of caregivers and care given by them. It was prepared by researchers by reviewing literature.

2.4.3. Barthel Index (BI) is a scale that was developed by Mahoney and Barthel and it evaluates all steps of daily life activities of patients (Mahoney and Barthel, 1965). It has been used to assess the independence level of patients. The validity and reliability studies were carried out with neurology patients by Küçükdeveci et al in our country (Küçükdeveci et al. 2000). Accordingly, internal consistency of Barthel Index was 0.93, competence level of Kappa was over 0.5, intra class correlation coefficient was 0.99, and Cronbach's alpha value was 0.93. Barthel Index scores were between 0-100 and scores between 0-20 referred to total dependency, scores between 21-61 referred to advanced dependency, scores between 62-90 referred to moderate dependency, scores between 91-99 referred to mild dependency, and 100 points referred to independency (Küçükdeveci et al. 2000).

2.4.4. Care Burden Scale (CBS) developed by Zarit, Reever and Bach-Peterson in 1980 and its reliability and validity was made by İnci and Erdem (İnci and Erdem, 2008). CBS consists of 22 expressions and it tries to determine the effect of caregiving on caregivers when they give care service. The scale has scores from 0 to 4, never, rarely, occasionally, often or always. Minimum 0 and maximum 88 points can be scored in the scale. The majority of the items in the scale are oriented towards social and emotional areas and getting high scores from the scale indicates that the level of problem is high. Scores between 0-20 points indicate that "there is no care burden", between 21-40 points refer to "t mild care burden", between 41-60 points refer to " moderate care burden" , and between 61-88 points refer to "heavy care burden". Validation study of CBS was examined to use scale's language equivalence, content validity, and structure validity methods by İnci in 2006. Internal consistency, item analysis and test-retest method were examined for reliability analysis. Internal consistency of scale was between 0.87 and 0.94, test-retest reliability was 0.71 and internal consistency was 0.95 (İnci and Erdem, 2008). Internal consistency was 0.85 in this study.

2.5. Data collection/procedure

Four trained researcher collected data in at the patients' home. Surveys were filled by researchers in face-to-face meetings.

2.6. Data analysis

The data were evaluated with SPSS 20.0 statistical package program. A p value < 0.05 was chosen for data's statistical significance. We were calculated the data with percentage, average, standard deviation, independent samples t test, Mann Whitney U, Kruskal Wallis tests.

3. Results

A total of 161 patient and caregiver participated in the study. Age average of patients is 66.90 ± 22.90 , caregivers are 50.55 ± 12.85 . Majority of patients are women (65.2% - 80.1%). 36% of patients and 85.1% of caregivers are married. More than half of both groups are housewives. Majority of patients (46.0%) are illiterate, majority of caregivers are primary-secondary graduates (53.4%). 23% of patients have no health insurance and 57.1% of them have less income than expense. 23.6% of caregivers have no health insurance and 44.1% of them have less income than expense (Table 1).

TABLE 1. Socio-Demographic characteristics of patients and caregivers (N=161)

Characteristics	Patient		Caregiver		
	$\bar{X} \pm SS$		$\bar{X} \pm SS$		
Age	66.90 ± 22.90		50.55 ± 12.85		
	min=5		min=25		
	max=100		max=90		
	n	%	n	%	
Sex	Female	105	65.2	129	80.1
	Male	56	34.8	32	19.9
Marital status	Married	58	36.0	137	85.1
	Single	28	17.4	9	5.6
	Divorced	75	46.6	15	9.3
Professional status	Housewife	91	56.6	112	69.5
	Worker or officer	8	5.0	31	19.3
	Retired	31	19.3	18	11.2
	Unemployed	31	19.3	-	-
Educational status	Illiterate	74	46.0	26	16.1
	Literate	28	17.4	9	5.7
	Primary/Secondary education	54	33.5	86	53.4
	High School or upper level	5	3.1	40	24.8
Health insurance	Yes	124	77.0	123	76.4
	No	37	23.0	38	23.6
Economic conditions	Income is less than expenses	92	57.1	71	44.1
	Income and expenses are equal	69	42.9	90	55.9

In the distribution of health problems of patients, Neuromuscular and neuromotor diseases were the most common reasons to need home care (57.5%). First three chronic diseases of patients were determined as Hypertension (44.7%), Cerebrovascular Diseases (44.1%) and Diabetes Mellitus. 54.7% of patients were fully dependent, 29.8% were on highest degree dependent, 13.8% were mid-level dependent, and 2.5% were slightly dependent. When using drugs were examined, it was determined that the patients most commonly used cardiovascular (52.2%), analgesic/anti inflammatory (43.5%), and central nervous system drugs (42.9%). 39.1% of patients had only physical disability, 52.8% have disabilities of 81% and above. It was determined that the most preferred assistive devices by patients were wheelchairs (17.4%) and pneumatic bed (16.1%) (Table 2).

TABLE 2. Distribution of health problems of patients

Issues		n	%
Reasons of receiving homecare*	Neuromuscular and neuromotor diseases	104	57.5
	Fractures	15	8.3
	Mental retardation	14	7.7
	Cancer	10	5.5
	Other (Eld, renal and cardiac disease, physical disability etc.)	38	21.0
Existence of chronic disease*	Hypertension	72	44.7
	Cerebrovascular disease	71	44.1
	Diabetes mellitus	49	30.4
	Coronary artery disease	40	24.8
	Other (Epilepsy, goitre, renal disease etc.)	27	16.8
Dependence level according to Barthel Index	0-20 points: Fully dependent	88	54.7
	21-61 points: Advanced dependent	48	29.8
	62-90 points: Moderate dependent	21	13.0
	91-99 points: Mild dependent	4	2.5
Using drugs*	Cardiovascular	84	52.2
	Analgesic/anti inflammatory	70	43.5
	Central nervous	69	42.9
	Psychiatric	46	28.6
	Endocrine	46	28.6
	Diuretic	45	28.0
	Vitamin and nutrition	42	26.1
	Respiratory	39	24.2
	Antibiotics	39	24.2
	Hematopoietic	35	21.7
	Other (Genitourinary, gastrointestinal, antineoplastic, ophthalmic)	53	33.0
Disability status	No	54	33.5
	Physically handicapped	63	39.1
	Physically and speech handicapped	20	12.4
	Physically, visually, and speech handicapped	11	6.8
	Physically, speech handicapped and hearing impairment	7	4.4
	Physically and visually handicapped	6	3.8
Disability status	No	69	42.9
	50-80%	7	4.3
	%81 and above	85	52.8
Using assistive device status*	Non-user	55	34.2
	Wheelchair	28	17.4
	Pneumatic bed	26	16.1
	Crutch or Walker	19	11.8
	Glasses	13	8.1
	Using more than one device	20	12.4

* Percentage of existing ones were given. More than one answer was marked

As it is stated in Table 3, 53.3% of the caregivers are the patients' daughters or daughters in law, and the 21.1% of them are their spouses. The caregiver has difficulties in hygiene practices (64%), changing the nappies (62.1%) and transferring/moving the patient (54%) the most. The majority of the caregivers (96.9%) live in the same house with the patient. It has been determined that 48.4% of the caregivers have been servicing for more than 5 years, and 87% of them have been servicing for more than 8 hours a day. 95% of the caregivers are pleased to service, and 57.8% of them are pleased with healthcare professionals' home care services. Only 7.5% of the caregivers have stated that they have received education to service in this area. 58.4% of the caregivers state that they do not get any help from anyone in giving care, and 82% of them state that they have difficulties in

servicing. 74.5% of the caregivers have mentioned “familial responsibilities” as a reason for giving care. 59.6% of the caregivers state that they do not experience any health issues after giving care (Table 3). It has been determined that 51.6% of the caregivers have mild burdens, and 37.3% of the caregivers have medium-level burdens. It has been determined that the people who say their burden is heavy form 7.5% of the caregivers while the ones who say they don't have any burdens form 3.7% of the caregivers. Total Care Burden Scale point of the caregivers is 41.32 ± 13.20 .

TABLE 3. Descriptive information about caregivers, the difficulties that they usually have

Factors		n	%
Kinship	Daughter/Daughter in law	86	53.3
	Spouse	34	21.1
	Son	17	10.6
	Mother	17	10.6
	Other (Father- Sibling- grandchild)	7	4.4
The issues that make difficulties in giving care*	Hygiene practises	103	64.0
	Changing diapers	100	62.1
	Transferring/moving the patient	87	54.0
	Caregivers' socialization	68	42.2
	Perineal care (Incontinence- catheter)	65	40.4
	Taking patient to the doctor	62	38.5
	Patients' socialization	59	36.6
	Economic problems	52	32.3
	Feeding	51	31.7
	Housework	51	31.7
	Preparing the medicines	50	31.1
	Communication	50	31.1
	Oral care	46	28.6
Staying in the same house with the patient	Making food	44	27.3
	Yes	156	96.9
Patient has a separate room	No	5	3.1
	Yes	120	74.5
Giving care duration	No	41	25.5
	5 years and more	78	48.4
	1-5 years	69	42.9
Giving care duration a day	6-11 months	14	8.7
	8 hours and more	140	87.0
	Less than 8 hours	21	13.0
Gladness of caregiving	Yes	153	95.0
	No	8	5.0
Gladness of home care services	Yes	93	57.8
	Partially	35	21.7
	No	33	20.5
Receiving education on caregiving	Yes	12	7.5
	No	149	92.5
Help in receiving care	Yes	67	41.6
	No	94	58.4
Having difficulties in caregiving	Yes	132	82.0
	No	29	18.0
Reasons to be a caregiver	Familial responsibility	120	74.5
	F.R. and nobody to give care	30	18.6
	Nobody to give care	8	5.0
	Economic contribution	3	1.9
Having health issues after caregiving	Yes	65	40.4
	No	96	59.6

* Percentage of existing ones were given. More than one answer was marked.

Comparison of CBS points according to some descriptive information about caregivers is given in Table 4. According to the caregiver's age, marital status, educational status, financial status, receiving help on caregiving and duration of caregiving, there hasn't been a statistically significant difference found among CBS points (respectively, $p=.240$; $p=.89$; $p=.85$; $p=.948$; $p=.409$; $p=.248$). It has been confirmed that women have lower CBS points than men when it is compared according to the sex of the caregivers, and the difference between them is statistically significant ($p=.008$). CBS point has been found to be 34.19 ± 11.57 with the ones who service for less than 8 hours a day, and it has been found to be 42.39 ± 13.14 with the ones who service for 8 hours or more. And the difference between them has been found to be statistically significant ($p=.008$) (Table 4).

TABLE 4. Comparison of CBS points according to some descriptive characteristics of caregivers (n=161)

Features	CBS points of caregivers		Statistical values	
	n	$\bar{X} \pm SS$		
Age	40 and below	43	43.35 ± 13.94	t=1.180 p=0.240
	41 and above	118	40.58 ± 12.91	
Gender	Woman	129	39.95 ± 13.01	t=-2.697 p=0.008
	Man	32	46.84 ± 12.70	
Marital status	Married	137	41.35 ± 13.38	U=-1616.000 p=0.894
	Not married	24	41.13 ± 12.40	
Educational Status	Secondary school or below	121	41.19 ± 12.46	t= -.190 p=0.850
	High school and above	40	41.70 ± 15.42	
Financial Status	Income is less than expense	71	41.24 ± 13.52	t=-.066 p=0.948
	They are equal	90	41.38 ± 13.02	
Getting help in caregiving	Yes	67	42.37 ± 14.72	t=.828 p=0.409
	No	94	40.56 ± 12.02	
Caregiving Duration	6-11 months	14	36.43 ± 7.87	KW=1.336 p=0.248
	1-5 years	69	41.28 ± 13.52	
	5 years +	78	42.23 ± 13.61	
Daily Caregiving Duration	less than 8 hours	21	34.19 ± 11.57	U=944.000 p=0.008
	8 hours and more	140	42.39 ± 13.14	

* t=student t test U=Mann-Whitney U test KW= Kruskal-Wallis test

Caregivers' knowledge and skill requirements on caregiving and perception of capability are given in Table 5. The areas where the caregivers' level of sufficiency are the lowest according to the patients' needs have been confirmed as follows: preventing decubitus (19.9%) and decubitus care (21.1%), carrying the patient with the proper method (19.9%), looking out for their own body mechanics (19.3%) and wound care (18.6%), vital measurements (16.8%), genital care (16.1%), stress management (15.5%), and constipation (14.9%).

TABLE 5. Caregivers' knowledge and skill capability on caregiving according to the patients' needs

Care Fields	Patient has needs %	Caregiver doesn't have information %	Caregiver doesn't have skills/ is not capable. %
Patient's dressing	96.5	2.5	2.5
Orally drug administration	83.2	2.5	2.5
Hand washing	82.6	3.1	3.1
Hygiene (Oral care, hand-face-eyes-foot-nail care etc.)	82.0	2.5	2.0
Carrying the patient from one place to another with the appropriate method	81.4	13.0	19.9
Genital care	76.4	9.9	16.1
Feeding process and cleaning	71.4	3.1	3.1
Wearing non-sterile gloves	68.3	9.9	13.7
Using specific equipments (maintenance, prosthesis, wheelchair etc.)	65.8	8.1	10.6
Constipation	62.7	8.7	14.9
Being careful about self body mechanics during caregiving	61.5	13.7	19.3
Universal precautions for infections	60.2	11.2	11.8
Following the changes on the skin (color, ecchymose, hematoma, moisture etc.)	58.4	11.2	15.5
Turning over the patient on the bed- positioning	57.8	7.5	13.0
Measuring the blood pressure	56.5	11.8	16.8
Insomnia	56.5	8.1	11.8
Planning activities together (spending time together, puzzles, card games etc.)	52.8	7.5	8.1
Giving a massage on the bed	52.2	12.4	16.8
Being unable to communicate with the patient (paralyzed patients or patients unable to speak etc.)	52.2	6.2	9.3
ROM exercises (patients with contracture and atrophy risks)	51.6	14.9	18.0
Using glasses, hearing aids, dentures etc.	50.3	6.8	8.7
Bathing care on the bed	46.6	10.6	14.3
Stress management	46.0	11.2	15.5
Rules of decubitus prevention	44.1	13.0	19.9
Taking the pulse	42.9	13.0	16.8
Choosing the foods concerning the disease	42.9	5.0	5.0
Anger management	42.2	10.6	14.3
Noting and reporting the observations on the patient	41.6	14.9	18.0
Rating the respiration	39.4	13.0	16.8
Measuring the body temperature	39.1	11.8	14.9
Approach to memory problems such as dementia-Alzheimer's	39.1	9.9	12.4
Giving urinalor bedpan	38.5	8.7	9.3
Decubitus care	36.6	13.0	21.1
Subcutaneous drug administration (insulin, anticoagulant etc.)	35.4	6.2	11.2
Urinary Catheter (bag and care)	34.8	9.3	12.4
Removing the contaminated equipments (needle tips etc.)	34.2	5.6	6.2
Rules of measuring the blood sugar	34.2	7.5	9.9
Wound care (dressing etc.)	33.5	9.3	18.6
Diarrhea	33.5	6.2	6.2

Laxative/Disimpaction administration	32.3	5.6	5.6
Using the glucometer	32.3	6.8	8.7
Sublingual administration (Captopril, digoxin etc.)	29.2	4.3	8.1
Drug administration to the eye	28.0	4.3	6.2
Oxygen therapy (dosage, cleaning, observing)	26.1	6.2	10.6
Nebulizer drug administration	25.5	5.0	5.6
Inhaler drug administration	23.0	5.0	6.8
Using BPAP devices at home	18.0	8.1	10.6
N/G or tube feeding	13.0	2.5	3.1
Drug administration trough N/G tube	13.0	2.5	3.1
Tracheostomy care	5.6	1.2	2.5
Transdermal drug administration	4.3	95.7	95.7
Gastrostomy care	3.1	96.9	96.9
Ostomy Care (colostomy-ileostomy etc.)	3.1	0.6	0.6

*Estimated according to the caregivers' statements.

4. Discussion

In this study, first three reasons for the patients to receive home care service were neuromuscular and neuromotor diseases, fractures and mental retardation. Işık et al, fractures were ranked as the first reason among the reasons requiring home care services, while hypertension, diabetes mellitus, cancer, heart diseases, Alzheimer's, joint diseases and neurological problems were among those reasons, as well (Işık et al. 2016). Nadarević-Štefanec et al (2011) has determined that 28.9% of the patients receiving home care services had circulatory system diseases, 13.2% of them had terminal diseases, 11.8% of them had musculoskeletal diseases and connective tissue disease, and 9.2% of them had nervous system diseases. These various indications may weigh on the necessity of the patient-centered estimation of training requirements of the patients who will potentially receive home care. Vast majority of the patients in our study were dependent individuals using cardiovascular, analgesic/anti-inflammatory and central nervous system medications. The rate of the patients who were not handicapped was 33.5%, the rate of the ones with 81% or more handicap situation was 52.8%, and large majority of them we using at least one assistive equipment. Health impairment, chronic disease or decrease in the independent functions increase the individuals' care requirements. Giving care to a handicapped relative is shown substantially as a reason for anxiety, depression and increased care burden (Karahan and İslam, 2013).

In our study, it has been found that 53.3% of the caregivers were the daughter/daughter in law of the patient, and 21.1% of them were the spouse of the patient. It has been determined that average age of the vast majority of the caregivers was 51, they were women, married, housewives and primary/secondary school graduates. It has been stated in the literature that vast majority of the caregivers were women, between the age of 35 and 50, married and housewives (Aşiret & Kapucu, 2013; Navaie-Waliser et al. 2002; Özel-Kızıl et al. 2014; Şirzai et al. 2015). This situation indicates that the traditional Turkish family structure still continues. Although there has been an increase in the requirement for formal home care services as the social values and behaviors have changed in the society, these indications supports the fact that the informal care has been continuing from past to present and mostly women perform this task in spouse, child, and parent roles (Aşiret and Kapucu, 2013; Karahan and İslam, 2013; Salama and El-Soud, 2012; WHO, 2008). It was seen that caregivers had difficulties in hygiene practices (64%), diaper care (62.1%), transfer/movement of the patient (54%) at most. In a study conducted to determine the difficulties that the caregivers faced with Alzheimer patients, it has been stated that caregivers faced difficulties in feeding (82%), communication (80%) and urinary incontinence (62%) at most (Akyar and Akdemir, 2009). In another study, it has been found that the vast majority of caregivers (65.3% of

them) had difficulties in transferring the patient, carrying the patient, communication, bladder care and personal care at most while they were serving as caregivers (Şırzai et al. 2015). Diversity of the results reveals the diversity of the difficulties that the caregivers may face according to the patient profiles, as well. In this study, another factor affecting the areas that caregivers had difficulties in was the fact that 54.7% of the patients are “fully dependent” according to the Barthel index.

In this study, it was stated that only 7.5% of the caregivers have received training on caregiving. Most of the caregivers (95%) were pleased to give care, 57.8% of them were pleased with the health professionals' home care services. More than 50% of the caregivers stated that they did not get any help from other people on caregiving, large majority of them had difficulties in caregiving. It has been confirmed that total CBS point of the caregivers was 41.32 ± 13.20 . Similar to this study, it has been found that the burden of the caregivers who gave care to paralyzed patients was at moderate level (Mollaoğlu et al. 2011). Akyar and Akdemir (2009) have presented that 64% of caregivers had difficulties with their families because of caregiving, and 40.6% of those who had difficulties could not get any support in caregiving. In the study of Işık et al (2016), it has been confirmed that the patients receiving home care services were pleased with the health professionals' training at medium level, and the rate of the ones who found the personnel's explanations insufficient has been found to be 21.3%. The indications of our research may weigh on that caregivers in the study group could not cope with the issues in the house. This situation implies that the consideration of the caregiving duration of the caregivers, the training requirement in caregiving, help requirement in caregiving and support while having difficulties are necessary.

The findings of our research showed that the caregiver's age, marital status, educational status, status of getting help in caregiving and caregiving duration did not affect CBS points ($p > 0.05$). According to the literature, factors such as caregivers' age, gender, marital status, kinship with the patient, educational status, financial status, patient's current disease and duration of caregiving affect the caregiving burden (Aşiret and Kapucu, 2013; Atagün et al. 2011; Mollaoğlu et al. 2011; Salama and El-Soud, 2012). It has been determined that the burden of illiterate caregivers who served for the dependent patient in daily activities and who had health problems was heavy (Mollaoğlu et al. 2011). In another study that examined the burden of caregiving with paralyzed patients and affecting factors; it has been found that there was no statistically significant difference among CBS points according to various factors such as the caregiver's age, educational status, marital status, social-economic status, status of getting help in caregiving and caregiving duration (Yıldırım et al. 2013). In this study, it has been found that female caregivers had lower CBS points than men and the difference between them was statistically significant ($p < 0.05$). This fact is not accordant with the literature. Some of the previous studies have suggested that the female caregivers had more burden and other studies have suggested that there was not a difference in terms of gender (Özel-Kızıl et al. 2014; Takano and Arai, 2005). It was determined that women get stressed more in caregiving (Leggett et al. 2011; Navaie-Waliser et al. 2002). It has been determined that single caregivers had higher CBS points compared to married ones (Gorgulu et al. 2016). According to these various results, it can be estimated that the task of caregiving to patients is given to women in Turkish society and it can be because of the facts that women take their current situations as an obligation and accept it and there is a possibility that women can express their feelings better. Moreover, along with men's lack of knowledge and skills in caregiving, factors such as the fact that they cannot get the necessary help and social support to maintain the caregiving may have increased their caregiving burden.

Even though caregiving is served more by women, it can be useful to carry out preventive psychological evaluations on male caregivers as much as female caregivers, as well. It has been determined in this study that 48.4% of caregivers have been serving for more than 5 years, 87% of them served for 8 hours and more a day. It has been found that CBS point of the ones who served for less than 8 hours a day equals to 34.19 ± 11.57 , and CBS point of the ones who served for 8 hours and more equals to 42.39 ± 13.14 , and there was a statistically significant difference found between them ($p < 0.05$). Similar to this study, there are studies indicating that caregiver's burden

increases as the caregiving duration increases (Aşiret and Kapucu, 2013; Karahan and İslam, 2013; Pinguart and Sorensen, 2007). In this study, the fact that the burden of the caregivers who served for partially self sufficient/dependent patient was at moderated level can weigh on the fact that patients had extra health issues and they had restrictions in performing their daily activities affected the caregiving burden of caregivers.

Considering the knowledge and skill/sufficiency status of the caregivers in caregiving, it has been found that the areas where caregivers' skill level was the lowest and they had difficulties at most were "decubitus prevention and decubitus care, carrying the patient with the appropriate method, being careful about their own body mechanics, wound care, vital measurements, genital care, stress management and constipation". In a quasi-experimental study identifying the home care services requirements of the bed-bound patients, it has been determined that the majority of the patients said that their hygienic care failed to satisfy and they had psycho-social issues; that they required information regarding their diseases, the medications they used, constipation, diarrhea and their nutrition and it has been confirmed that the training the patients received decreased the number of issues they had at home (Akdemir et al. 2011). It has been confirmed that 65% of the patients had sleep disorders and pain, 55.9% of them went through contracture, deformity, and atrophy because of reasons such as the facts that they could not actively exercise or their need of physiotherapist was not provided, 53.1% of them could not participate in social activities and their need of healthcare personnel was not provided, 37.3% of them had bedsore, 36.2% of them had hygiene care-related problems, 16.9% of them suffered from lung, perineum, oral, vascular access, foot, eyes and skin infections, and 9.6% of them required information about their disease, and it has been underlined that health care team should organize training and consultancy services (Taşdelen and Ateş, 2012). In another study that has been carried out to identify the difficulties caregivers of Alzheimer patients face; it has been found that the patients ha most difficulties in nutrition (82%), communication (80%), urinary incontinence (62%), hallucination (62%) and sleep disorders (56%). It has been detected that 44% of the caregivers needed information about caregiving and the areas that they needed to learn were coping with the behavioral change (36.4%), nasogastric, urinary catheter (33.4%), and self care practices (55.6%) (Akyar and Akdemir, 2009). In a study which the activities of people who received home care services and the activities of people who did not were compared, the rate of unplanned hospitalization and having difficulties in daily activities (getting dressed, bathing, needing toilet, eating etc.) were lower with the ones receiving home care services (Health Quality Ontario, 2013). These results weigh on the fact that home care services are not enough in Turkey and formal and informal care support should be developed. It is very important to provide the cooperation of nurses, doctors, physiotherapists and other teams in coping with these problems that affect the patient and the adaptation of the caregivers to patient's disease.

Limitations of the study: We evaluated the need for knowledge and skills according to the caregiver's own statement. For this reason, the results do not really indicate how well a person knows or is able to do. It can be considered within the limitations of this research.

5. Conclusion and suggestions

It has been determined that male caregivers who worked for home care services had more burden than female caregivers, the caregiving burden increased as the daily caregiving duration increased, there was not a statistically significant difference among CBS points of the caregivers according to their age, educational status, marital status, social-economic status status of getting help in caregiving and duration of caregiving, and women worked as caregivers more. The caregivers were pleased with caregiving and home care services. It has been confirmed that caregivers had knowledge and skill requirements on many areas according to the patients' needs. In accordance with these results, it can be recommended to;

-Conduct studies to decrease the caregiving burden by identifying the difficulties that the caregivers have and meeting the support needs of the caregivers that are under risk,

- Provide the professional educational support to the caregivers for the problems they have most according to their need of information and patients' need,
- Initiate the home care services with a care coordinator who estimates the needs of the patient and the patient's relatives as of the moment the patient is discharged from the hospital, so as to fulfil the caregivers' knowledge and skill requirements according to the patient's needs,
- Routinely provide training to the patient and the relatives on symptoms and life style management, medications and other health topics by visiting the patient at home within the 24 hours after the patient is discharged from the hospital,
- Develop a support system in cooperation with health-social institutions and organizations and the family members in order to decrease the caregiving burden of the caregivers and to help them fulfil their responsibilities concerning their other roles.

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References

- Akdemir, N., Bostanoğlu, H., Yurtsever, S., Kutlutürkan, S., Kapucu, S., & Özer, Z. C. (2011). Needs of home care services for the bedridden patient's problems living in their home. *Dicle Medical Journal* [Yatağa bağımlı hastaların evde yaşadıkları sağlık sorunlarına yönelik evde bakım hizmet gereksinimleri. *Dicle Tıp Dergisi*], 38(1),57-65. (in Turkish).
- Akyar, İ., & Akdemir, N. (2009). Strains of caregivers of Alzheimer patients. *Hacettepe University Faculty of Health Sciences Nursing Journal* [Alzheimer hastalarına bakım verenlerin yaşadıkları güçlükler. *Hacettepe Üniversitesi Sağlık Bilimleri Fakültesi Hemşirelik Dergisi*], 16(3),32-49. (in Turkish).
- Aşiret, G. D., & Kapucu, S. (2013). Burden of caregivers of stroke patients. *Turkish Journal of Neurology*, 19(1),5-10.
- Aşiret, G. D., & Kapucu, S. (2012). Care burden of the patient relatives who take care of the patients with stroke. *Turkish Journal of Research & Development in Nursing* [İnmeli hastalara bakım veren hasta yakınlarının bakım yükü. *Hemşirelikte Araştırma Geliştirme Dergisi*], 14(2),73-80. (in Turkish).
- Atagün, M. İ., Balaban, Ö. D., Atagün, Z., Elagöz, M., & Özpolat, A. Y. (2011). Caregiver burden in chronic diseases. *Current Approaches in Psychiatry* [Kronik hastalıklarda bakım veren yükü. *Psikiyatride Güncel Yaklaşımlar*], 3(3),513-552. (in Turkish).
- Gopalan, N., & Brannon, L. A. (2006). Increasing family members' appreciation of family care giving stress. *J Psychol*, 140(2),85-94.
- Gorgulu, U., Polat, U., Kahraman, B. B., Ozen, S., & Arslan, E. (2016). Factors affecting the burden on caregivers of stroke survivors in Turkey. *Medical Science and Discovery*, 3(4),159-65.
- Health Quality Ontario. (2013). In-home care for optimizing chronic disease management in the community: an evidence-based analysis. *Ontario Health Technology Assessment Series*, 13(5):1–65. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3804052/pdf/ohtas-13-65.pdf>
- İnci, F. H., & Erdem, M. (2008). Validity and reliability of The Burden Interview and Its Adaptation to Turkish. *Atatürk University Nursing School Journal* [Bakım Verme Yükü Ölçeği'nin Türkçe'ye uyarlanması geçerlilik ve güvenilirliği. *Atatürk Üniversitesi Hemşirelik Yüksekokulu Dergisi*], 11(4),85-95. (in Turkish)
- Işık, O., Kandemir, A., Erişen, M. A., & Fidan, C. (2016). Profile of patients who use home care health services and evaluation of provided service. *Hacettepe Health Administration Journal* [Evde sağlık hizmeti alan hastaların profili ve sunulan hizmetin değerlendirilmesi. *Hacettepe Sağlık İdaresi Dergisi*], 19(2),171-186. (in Turkish)
- Karahan, A. Y.,& İslam, S. (2013). A comparative study on caregiver burden of caregivers to physically disabled, pediatric and geriatric patients. *Journal of Marmara University Institute of*

- Health Sciences* [Fiziksel engelli çocuk ve yaşlı hastalara bakım verme yükü üzerine bir karşılaştırma çalışması. *Marmara Üniversitesi Sağlık Bilimleri Enstitüsü Dergisi*], 3(1),S1-S7. (in Turkish)
- Kucukdeveci, A. A., Yavuzer, G., Tennant, A., Suldur, N., Sonel, B., & Arasil, T. (2000). Adaptation of the modified Barthel Index for use in physical medicine and rehabilitation in Turkey. *Scand J Rehabil Med*. 32(2),87-92.
- Küçükgüçlü, Ö., Esen, A., & Yener, G. (2009). The reliability and validity of the Caregiver Burden Inventory in Turkey. *Journal of Neurological Sciences* [Bakım Verenlerin Yükü Envanterinin Türk toplumu için geçerlik ve güvenilirliğinin incelenmesi *J.Neurol.Sci.Turk*], 26(1),060-073. (in Turkish)
- Leggett, A. N., Zarit, S., Taylor, A., & Galvin, J. E. (2011). Stress and burden among caregivers of patients with Lewy body dementia. *The Gerontologist*, 51(1),76-85.
- Mahoney, F.I., & Barthel, D. (1965). Functional evaluation: The Barthel Index. *Md State Med J*, 14:61-65.
- Mollaoglu, M., Tuncay, F.Ö., & Fertelli, T.K. (2011). Care Burden Of Care Givers Of Stroke Patients And Related Factors. *Dokuz Eylül University School of Nursing Electronic Journal* [İnmeli hasta bakım vericilerinde bakım yükü ve etkileyen faktörler. *Dokuz Eylül Üniversitesi Hemşirelik Yüksekokulu Elektronik Dergisi*], 4(3),125-130. (in Turkish)
- Nadarević-Štefanec V., Malatestinić Đ., Mataija-Redžović A. & Nadarević T. (2011) Patients satisfaction and quality in home health care of elderly Islanders. *Coll Antropol*, 35(2),213-216.
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2002). When the caregiver needs care: the plight of vulnerable caregivers. *Am J Public Health*, 92(3),409-413.
- Özel-Kızıl, E.T., Altıntaş, H.Ö., Baştuğ, G., Durmaz, N., & Altunöz, U. (2014). The effect of agitation on care givers'burden in patients with dementia. *Turkish Journal of Geriatrics/ Turk Geriatri Derg*, 17(3),256-261.
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal care givers: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci*, 62(2),P126-P137.
- Salama, R. A. A., & El-Soud, F. A. A. (2012). Caregiver burden from caring for impaired elderly: A cross-sectional study in rural lower Egypt. *Ital J Public Health*, 9(4),e8661-10.
- Şirzai, H., Delialioğlu, S. Ü., Sarı, İ. F., & Özel, S. (2015). Stroke and caregiver burden. *J PMR Sci* [İnme ve bakım verme yükü. *Fiziksel Tıp ve Rehabilitasyon Bilimleri Dergisi*], 18(3),162-169. (in Turkish)
- Takano, M., & Arai, H. (2005). Gender difference and caregivers' burden in early-onset Alzheimer's disease. *Psychogeriatrics*, 5(3),73-77.
- Taşdelen, P.,& Ateş, M. (2012). The needs of home care patients and the burdens of their caregivers. *Journal of Nursing Education and Research* [Evde bakım gerektiren hastaların bakım gereksinimleri ile bakım verenlerin yükünün değerlendirilmesi. *Hemşirelikte Eğitim ve Araştırma Dergisi*], 9(3),22-29. (in Turkish)
- World Health Organization. (2008). Home Care in Europe: The Solid Facts. Milan, Italy. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0005/96467/E91884.pdf.
- Yıldırım, S., Engin, E., & Başkaya, V. A. (2013). The burden of caregivers of stroke patients and the factors affecting the burden. *Archives of Neuropsychiatry* [İnmeli hastalara bakım verenlerin yükü ve yükü etkileyen faktörler] *Noropsikiatri Arsivi*, 50(2),169-174. (in Turkish)